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No. 07-1178

In the
Supreme Court of the United States

JOEL HJORTNESS, a minor, by and through his Parents and Legal Guardians ERIC HJORTNESS and GAIL HJORTNESS, ERIC HJORTNESS, and GAIL HJORTNESS,

Petitioners,

– v. –

NEENAH JOINT SCHOOL DISTRICT,

Respondent.

ON PETITION FOR A WRIT OF CERTIORARI
TO THE UNITED STATES COURT OF APPEALS
FOR THE SEVENTH CIRCUIT

BRIEF FOR *AMICUS CURIAE* AUTISM SPEAKS

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Autism Speaks' Motion for Leave to File Brief as *Amicus Curiae*

Comes now Autism Speaks to request leave to enter the above-referenced case and file a brief as *amicus curiae* pursuant to Rule 37. In support of its motion, Autism Speaks states:

1. In recent years, the autism community has been growing at an unprecedented rate, with the NIH and the CDC each estimating that, currently, 1 out of 150 children born today will be diagnosed with an autism disorder.

2. Autism Speaks is a national, not-for-profit organization dedicated to increasing awareness of autism spectrum disorders, funding research into the causes, prevention, treatments and potential cures for autism, and advocating for the needs of affected families.

3. Following mergers with other national autism organizations, Autism Speaks is now the largest not-for-profit organization in the world by resources dedicated to autism research, education and treatment and has chapters across the United States, Canada, and the United Kingdom.

4. Autism Speaks works closely with federal and state governments, as well as the U.S. military, to meet the needs of the ever-growing population of children with autism and parents of children with autism for access to treatment and education.

5. Autism Speaks has established a Federal Legal Appeals Project ("FLAP"), a national *pro bono* initiative at the federal level. Further detail concerning the mission and activities of Autism

Speaks and its FLAP are available on the Autism Speaks informational website, www.AutismSpeaks.org. Most recently, Autism Speaks filed an *amicus curiae* brief in the Tom F. case before the United States Supreme Court.

6. Autism Speaks seeks leave of court, in consent of Petitioners, to invoke *amicus* status and to file its proposed *amicus* brief in the form annexed hereto, supporting Petitioner's position on this appeal. Respondent will not consent to such relief, but Petitioners Joel Hjortness, Eric Hjortness, and Gail Hjortness have done so in writing (*see* Exhibit A).

7. Autism Speaks has absolutely no corporate affiliation or other relationship with the parties to this appeal. Autism Speaks seeks *amicus curiae* status because the core issues presented in this appeal are extremely important issues that affect the entire autism community. The affected community is going to be large given that the CDC and NIH report that, currently, 1 in 150 children born today will be diagnosed with an autism spectrum disorder.

8. Autism Speaks supports petitioner's position. If, as requested, this Court grants Autism Speaks' motion, the annexed proposed brief shows that Autism Speaks will be able to aid this Court's consideration by making the following points, among others:

- ✓ Congress is increasingly treating autism as a national priority;
- ✓ With appropriate placements, programming and services, many of the developmental

deficits associated with autism can be ameliorated;

- ✓ Inasmuch as autism is a serious communication disorder, it is essential that parents of children with autism have a voice and input at their child's IEP meeting that is meaningful and given bone fide consideration by the local educational agency; and

- ✓ The record here reflects that respondent impermissible "predetermined" petitioner Joel Hjortness's education program and in so doing, deprived Joel's parents of meaningful participation in the IEP process.

WHEREFORE, Autism Speaks and Gary S. Mayerson respectfully request that the Court grant this motion to file a brief as *amicus curia*.

Dated: April 17, 2008
New York, New York

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Interest of *Amicus Curiae*[1]

Amicus curiae Autism Speaks is a not-for-profit organization dedicated to increasing awareness of autism spectrum disorders, funding research into the causes, prevention, treatments and potential cures for autism, and advocating for the needs of affected families. Following mergers with other national autism organizations, Autism Speaks is now the largest not-for-profit organization in the world by resources dedicated to autism research, education and treatment and has chapters across the United States, Canada, and the United Kingdom. Autism Speaks works closely with federal, state and local governments, as well as the U.S. military, to meet the needs of the ever-growing population of children with autism and parents of children with autism for access to treatment and education.

Autism Speaks can offer valuable insights into the special educational challenges faced by children with autism and their families and the potential impact of the Court's decision on thousands of families across the nation who struggle at educational planning (IEP) meetings in an effort to secure effective teaching and programming.

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[1] Pursuant to this Court's Rule 37.6 we note that no part of this brief was authored by counsel for any party, and no person or entity other than Autism Speaks, its members, or its counsel made a monetary contribution to the preparation or submission of the brief. This brief was filed with the written consent of Petitioners, but not Respondent.

Early, intensive and effective special education services are critical to give a young child the chance to remediate and overcome the symptoms of autism and to grow into a productive, self-sufficient member of society.

Since autism is, at its essence, a serious communication disorder, it is essential that parents have a voice at IEP meetings that is genuinely and meaningfully considered by the local educational agency. Where, as here, the IEP result is impermissibly "predetermined," the child is deprived of a FAPE and the child's parents are deprived of their independent IDEIA entitlements. Winkelman v. Parma City Sch. Dist., 127 S.Ct. 1994 (2007).

The result advocated by the Respondent would jeopardize parents' ability to secure appropriate services for their child at precisely the point when an appropriate program is most critical and, conversely, when the damage caused by an inappropriate placement is the gravest. The harm that an inappropriate program can cause to a child's development during this window of opportunity can never be fully corrected.

Preliminary Statement

Autism, a pervasive and devastating developmental disorder, is a 24-7 workaholic that does not know how to take a break or holiday. Without appropriate and effective teaching and intervention, autism ruins lives and destroys families. Absent appropriate and effective intervention, children with autism grow up to be adults with autism, often requiring costly and sometimes lifelong institutional care. Considering that the National Institutes of Health and the Center for Disease Control are reporting that 1 in 150 children born today will be diagnosed with an autism spectrum disorder, effective and timely intervention is absolutely critical, not only for the child and the child's family, but for society in general.[2]

Although Congress has never defined specifically what a "free and appropriate education" ("FAPE") must consist of (presumably because of the Act's "individualization" requirement), twenty five years ago, the Supreme Court held that the educational (FAPE) benefit required under IDEA must be more than a mere *di minimus* benefit. Board of Educ. v. Rowley, 458 U.S. 176 (1982). *See also* O'Toole v. Olathe Dist. Schs. Unified Sch. Dist. No. 233, 144 F.3d 692 (10th Cir. 1998). *Cf.* Frank G. v. Board of Educ., 459 F.3d 356 (2d Cir. 2006), *cert denied*, Board of Educ. v. Frank G., 2007 U.S. LEXIS 11520 (U.S. Oct. 15, 2007) ("While the IDEIA does not require

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[2] Until relatively recently, autism was a rarely-diagnosed and little-known condition, but is now more prevalent among children than Down syndrome, diabetes, cystic fibrosis, and cancer.

states to maximize the potential of handicapped children...it must provide such children with "meaningful access" to education....[the IEP] must be "likely to produce progress, not regression") (internal citations omitted); Cypress-Fairbanks Indep. Sch. Dist. v. Michael F., 118 F.3d 245, 248 (5th Cir. 1997) (IEP must be likely to produce progress, not regression).

In Deal v. Hamilton County Board of Educ., 392 F.3d 840 (6th Cir. 2004), a unanimous Sixth Circuit, held that "predetermination" of the IEP by the local educational agency amounts to a serious procedural and substantive FAPE deprivation because it deprived parents of meaningful participation in the IEP process and thus prevents genuine individualization of the IEP.

Accordingly, the mere physical presence of parents at an IEP meeting is not enough. Nor is it enough that parents are "allowed" to ask questions. Where, as here, the IEP result has been predetermined by the school district, the IEP process is turned into a sham.

In order to have public confidence in the integrity of the IEP system, parents must be confident in the knowledge that the result has not been predetermined. All too often, for children with autism, their parents are their only hope for a voice in the development of what is supposed to be an "individualized" IEP. Predetermination effectively silences, in advance, that voice.

Argument

A. Congress is increasingly treating Autism as a national priority

As the incidence of Autism Spectrum Disorder has mushroomed, Congress increasingly has treated Autism as a national priority. In recent years, autism has grown dramatically more prevalent. In 1961, it was confidently asserted that "[i]nfantile autism is a relatively rare form of schizophrenia and is not important from an epidemiological point of view." C.B. Ferster, *Positive Reinforcement and Behavioral Deficits of Autistic Children*, 32 CHILD DEVELOPMENT 437, 437 (1961), *reprinted in* CLASSIC READINGS IN AUTISM 53 (Anne M. Donnellan ed., 1985). Even in 1993, shortly after the Department of Education began collecting statistics on autism, it classified only 19,058 children between 6 and 21 as having autism.[3] Office of Special Education and Rehabilitative Services, Department of Education, 26TH ANNUAL (2004) REPORT TO CONGRESS ON THE IMPLEMENTATION OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (2006). But in 2005, the Department of Education reported 192,643 autistic students between the ages of 6 and 21 – a more than tenfold increase. Office of Special Education and

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[3] Autism was added as a specifically-identified category of disability under IDEA by the Education of the Handicapped Act Amendments of 1990, Pub. L. 101-467, §101, 104 Stat. 1103, 1142 (1990). It is very difficult to determine the prevalence of autism before the 1990s.

Rehabilitative Services, Office of Special Education Programs, U.S. Department of Education, Data Analysis System (DANS), 1976-2005, *Table 1-3, Students ages 6 through 21 served under IDEA, Part B, by disability category and state: Fall 2005.* The Centers for Disease Control report rates as high as 1 in every 150 children. Catherine Rice, *Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002*, 56 MORBIDITY AND MORTALITY WEEKLY REPORT SS-1, 12 at 12 (Feb. 9, 2007) ("CDC, *14 Sites Study*"). With some 24,000 children with autism born each year, Autism Spectrum Disorder is now more common among children than Down syndrome, diabetes, cancer, cystic fibrosis, hemophilia, and sickle cell disease. S. Rep. No. 109-318 at 3 (2006).

As the incidence of autism has grown, Congress increasingly has made autism research and education a national priority. Autism was specifically identified as a disability under IDEA in 1991. *See* 20 U.S.C. §1401(3)(a)(i); Education of the Handicapped Act Amendments of 1990, Pub. L. 101-467, Title I, §101, Title IX, §901(b)(10) to (20), 104 Stat. 1103, 1142, 1143 (1990). The Children's Health Act of 2000 directed the National Institutes of Health to expand and intensify autism research and mandated the creation of an Interagency Autism Coordinating Committee to coordinate autism research and other efforts within the Department of Health and Human Services. Children's Health Act of 2000, Pub. L. 106-310, Title I, 114 Stat. 1101 (2000). In 2004, IDEA was amended to encourage the Department of Education to support the development of programs

to train special education teachers in autism disorders, and provide technical assistance and in-service training to schools and personnel servicing children with autism spectrum disorders. 20 U.S.C. §1462(b)(2)(G), 20 U.S.C. §1463(c)(8)(D). *See* Individuals with Disabilities Education Improvement Act of 2004, Pub. L. 108-446, Title I, 118 Stat. 2647, 2677 & 2682 (2004).

Most recently, Congress enacted the Combating Autism Act of 2006 to dramatically increase funding for autism research, detection and intervention and to promote interagency coordination of autism-related activities through the NIH. *See* Combating Autism Act of 2006, Pub. L. 109-416, 120 Stat. 2821 (2006); S. Rep. No. 109-318 at 18-20.

B. With appropriate placements, programming and services, many of the developmental deficits associated with Autism can be ameliorated

Autism is a spectrum disorder encompassing a range of developmental disorders related to impaired social function, impaired communication and repetitive, stereotyped behaviors. The degree and manifestation of impairments can vary dramatically from individual to individual, and the spectrum of disorders includes Asperger's Disorder and Pervasive Developmental Disorder, Not Otherwise Specified ("PDD-NOS"). *See* DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS, FOURTH EDITION, TEXT REVISION at 69-75 (4th ed. 2000) ("DSM-IV-TR"); S. Rep. No. 109-318, 2-3 (2006). Most children with autism show an "inability to relate themselves in the ordinary way to people and situations from the

beginning of life." Leo Kanner, *Autistic Disturbances of Affective Contact*, 2 NERVOUS CHILD 217 (1943), *reprinted in* CLASSIC READINGS IN AUTISM at 41 (Anne M. Donnellan ed., 1985) (emphasis omitted). Impaired communication is another classic symptom of autism. Approximately 40 percent of children with autism do not talk, and others have difficulty learning to use language for communicative purposes. S. Rep. No. 109-318 at 2; DSM-IV-TR at 70. Many children with autism also demonstrate restricted and stereotypical patterns of behavior or interests, an insistence on predictability, and great difficulty coping with unexpected changes to their routine. S. Rep. No. 109-318 at 3; DSM-IV-TR at 71.

Symptoms generally manifest early, usually before the child's third birthday and as soon as eighteen months or earlier; in some cases symptoms are present almost from birth.[4] S. Rep. No. 109-318 at 3, 9; Autism Spectrum Disorder Expert Working Group, Interagency Autism Coordinating Committee, National Institute of Mental Health, Department of Health and Human Services, AUTISM SPECTRUM DISORDERS ROADMAP (May 16, 2005) ("Roadmap"). Yet children with autism frequently are not identified until after they have entered the public school system. S. Rep. No. 109-318 at 3, 9; Roadmap at 8.[5]

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[4] The Working Group was created by the Interagency Autism Coordinating Committee at the National Institute of Mental Health. S. Rep. No. 109-318 at 2.

[5] With a median age at diagnosis of 52-56 months, half of autistic children are not diagnosed until they are nearly 5 years old or later. Catherine Rice, *Prevalence of Autism Spectrum Disorders: Autism and Developmental Disabilities Monitoring*

While the cause or causes of autism are still unclear, there is broad agreement that the symptoms of autism often can be significantly ameliorated. Appropriate education offers the possibility that children with autism can achieve self-sufficiency and become functioning, contributing members of society rather than permanent financial and emotional burdens on their families and on the public treasury.[6]

Parents cannot allow their child to languish in an inappropriate setting when every passing moment erodes potential benefits that can never be regained. For these children and their parents, "every moment counts." Laurie Tarkan, *Autism Therapy Is Called Effective, but Rare*, N.Y. TIMES, Oct. 22, 2002 (describing the "horrible feeling of time slipping away and nothing being done" when parents of children with autism don't have access to appropriate treatment); *see also* County Sch. Board of Henrico County v. R.T., 433 F. Supp. 2d 692, 696 (E.D.Va. 2006) ("a critical window of developmental opportunity was closing" for a child who was not receiving an adequate public education). "Children

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Network, Six Sites, United States, 2000, 56 MORBIDITY AND MORTALITY WEEKLY REVIEW SS-1, 1 at 1 (Feb. 9, 2007). In some locations, the median age of diagnosis is 66 months, meaning that half of children diagnosed with autism are not identified until after they are more than 5 ½ years old. CDC, *14 Sites Study* at 20.

[6] For descriptions of autistic children who have grown into productive – even remarkable – adults, *see, e.g.*, Oliver Sacks, AN ANTHROPOLOGIST ON MARS 244-296 (1995); Clara Claiborne Park, EXITING NIRVANA (2001); Stephen M. Shore, BEYOND THE WALL (2001); Kamran Nazeer, SEND IN THE IDIOTS (2006).

with autism can't afford to waste a second... With the right kind of early intervention, they can learn. Without it, there's no hope." Leslie C. Feller, *When Autistic Child's Growth Is at Stake*, N.Y. TIMES, Apr. 25, 1999 (internal quotation omitted).

Conclusion

For the foregoing reasons, *amicus curiae* Autism Speaks respectfully requests that this Court reverse the judgment of the Seventh Circuit Court of Appeals and grant such other and further relief as it deems just and proper.

Dated: April 17, 2008
New York, New York

Respectfully submitted,

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